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AUTHOR Viisola, Michelle
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ABSTRACT

This report summarizes statistical data relating to children with visual impairments, including incidence, causes, and education. Data include: (1) prevalence estimates that indicate 1 percent of persons under the age of 18 in the United States have a visual impairment that cannot be corrected with glasses; (2) the leading cause of childhood blindness is a vitamin A deficiency; (3) 24,877 students aged 6-21 received vision services during 1994 to 1995, representing .5 percent of all students receiving services; (4) students with visual impairments were more likely than other students with disabilities to have an A average in high school and to meet or exceed requirements in English, math, foreign languages, and computer science; (5) the average per pupil expenditure for programs in visual impairment for 1985-1986 was \$4,068 for preschool, \$6,181 for self-contained classrooms, and \$3,395 for resource rooms; and (6) only 29 percent of youth with visual impairments were competitively employed 3-5 years following secondary school. (Contains 32 references.) (CR)

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Statistics on Children with Visual Impairments

Prepared by:
Michelle Viisola, MA
National Center for Vision and Child Development
of Lighthouse International
April 1999

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Introduction

In 1995 The Lighthouse National Center for Vision and Child Development began compiling statistics on childhood visual impairments in order to provide accurate information through its information and resource service. Professionals in the vision field participated in a workshop to generate questions that they would like to have answered. These questions are addressed in Statistics on Children with Visual Impairments, a compilation of statistical information.

It will not surprise most people that we still cannot with complete confidence, answer the question "How many children in the United States have visual impairments" or "How many children are born each year with visual impairments." Educators, especially those responsible for teacher preparation, have been concerned for some time about the incomplete information available on the number of children with visual impairments. We hope that this document will increase awareness and promote discussion of the methods of collecting information and encourage those who are new to the field to participate in the dialogues that examine the implications of incomplete data.

The data that we have included in this manual are the most recent, clearly defined, and commonly referred to in reports and journals. Readers should be aware that each estimate applies specifically to data collected at a specific time from a specific population. Estimates will vary, depending on definitions and the population surveyed or registered. The statistics in this manual were gathered from a variety of sources and should be cited accordingly, using the reference list provided. It is also recommended that the original document be reviewed in order to get an in-depth understanding of the context within which the statistic was developed.

We invite anyone reading this document to submit comments, suggestions, and additional sources. In this way, we plan to continually update the document. If we reach our goal, this document will serve as a repository for statistics on children with visual impairments.

If you have comments, suggestions, or additional information, please contact Michelle Viisola, Lighthouse International, 111 East 59th Street, New York, NY 10022; phone: (212) 821-9491; fax: (212) 821-9491; email: mbeck@Lighthouse.org.

PREVALENCE ESTIMATES

Visual Impairment: U.S. Only¹

Based on data from the 1994 National Health Interview Survey 1% of persons under the age of 18 are visually impaired, defined as *blindness in one or both eyes, or any other trouble seeing even when wearing glasses*, representing 609,000 children and youths. (Adams & Marano, 1995).

Severe Visual Impairment: U.S. Only

An estimated 95,410 children and youths under 18 years of age (.2%) are severely visually impaired, defined as the *inability to see to read ordinary newspaper print even when wearing glasses (includes blindness in both eyes)* (Nelson & Dimitrova, 1993).²

Legally Blind: U.S. Only

National estimates for legal blindness, defined as *clinically measured visual acuity of 20/200 or less or a visual field in the better eye after optimal correction of 20 degrees or less*, indicate that 2,561 children under 5 (.01%) and 50,699 between the ages of 5-19 (.09%) are legally blind (Chiang, Bassi, & Javitt, 1992).³

Childhood Blindness: Worldwide

An estimated 1.4 million children (age 14 and under) in the world are classified as blind, defined as a *corrected visual acuity in the better eye of less than 3/60 (count fingers at 3m) or a corresponding visual field loss in the better eye with best possible correction* (Thylefors, Négrel, Pararajasegaram, & Dadzie, 1995).

Worldwide estimates are also available by region for persons under 16 years in a 1992 document.

Worldwide 1,494,000 children are blind, defined as *a person under 16 years of age with corrected visual acuity in the better eye of less than 3/60 (count fingers at 3m) or a central visual field of less than 10 degrees* (World Health Organization, Prevalence of blindness, 1992).⁴

Region	Estimated number of blind children	Blindness Prevalence
Africa	264,000	.11%
Latin America	78,000	.06%
North America, Europe, Japan, Oceania, former USSR	72,000	.03%
Asia	1,080,000	.09%
Total	1,494,000	

CAUSES OF BLINDNESS⁵

Causes of Childhood Blindness: Worldwide

Vitamin A Deficiency (Xerophthalmia)

A recent analysis of data indicates that vitamin A deficiency is the leading cause of childhood blindness. It was estimated that 70% of the 500,000 children who become blind annually do so because of xerophthalmia. This corresponds to a prevalence of roughly 1 million in view of the high mortality among affected children. (Thylefors, et al., 1995).⁶

Causes of Childhood Blindness: U.S Only

Amblyopia and Strabismus

It is estimated that between 1 and 4% of the childhood population is affected by strabismus, and 1 to 2% suffer from amblyopia (National Eye Institute, 1993).

Congenital Cataracts

Among children under 5 years of age, prenatal cataract is the leading cause of legal blindness, accounting for 16% of all cases (National Society to Prevent Blindness, 1980).⁷

Cortical Visual Impairment (CVI)

Cortical visual impairment is defined as a *temporary or permanent visual loss caused by disturbances of the posterior visual pathways and/or occipital lobes*. The vast majority of children with CVI have residual vision (Jan & Wong, 1991).

In developed countries, CVI has become more frequent (Blind Babies Foundation Registry, northern California, unpublished data) and can be considered one of the major causes of visual handicap in children of developed regions (Good, et al., 1994).

Glaucoma

Infantile glaucoma occurs in 1 out of 10,000 live births (Teplin, 1995).

Optic Nerve Atrophy

Optic nerve atrophy accounts for 12% of all cases of legal blindness in children (National Society to Prevent Blindness, 1980).

Retinopathy of Prematurity (ROP)

Retinopathy of prematurity (ROP) is characterized by the abnormal growth of blood vessels in retina of premature infants. Infants in whom ROP is diagnosed during the perinatal period are at risk for ocular abnormalities and for deficits in visual function.⁸

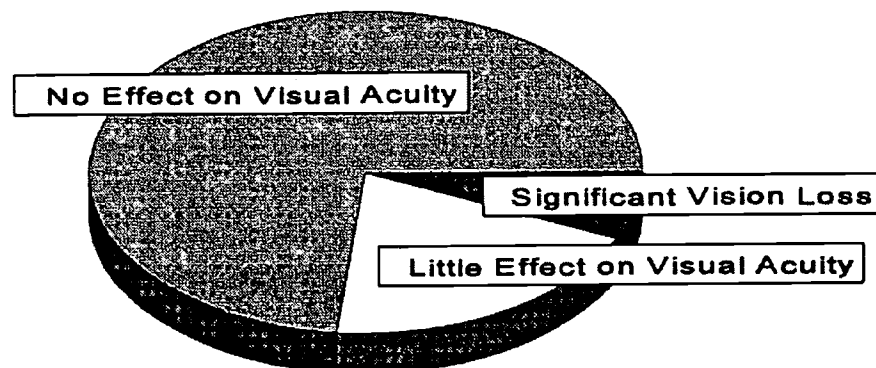
The following data are from The Multicenter Cryotherapy for Retinopathy of Prematurity (CRYO-ROP) study reported according to international classification based on the severity of ROP. The data were collected from 4,099 infants born between January 1986 and November 1987 with birth weights of less than 1251 grams.

Of 4,099 infants in the CRYO-ROP study:

- 2,699 (65.8%) developed some degree of ROP, with no effect on visual acuity.
- 730 (17.8%) were classified as prethreshold, with little effect on visual acuity.
- 246 (6%) were classified as threshold in one or both eyes. Within this group of 246 infants, 123 (50%) were blind and 123 (50%) had visual acuity that was significantly below normal. For the group of 123 infants with visual acuity significantly below normal, cryotherapy improved 49 (40%) of the cases.
- For each 100—gram decrease in birth weight, there was a 27% higher risk that an infant would develop threshold ROP (Dobson & Quinn, 1996).

CRYO-ROP Study

Degree of Vision Loss of Infants Who Developed ROP



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Multiple Impairment

According to "Registry of Early Childhood Visual Impairments in Central and Northern California," a report by The Blind Babies Foundation, of 971 children born with visual impairments in the years 1980 to 1995, 572 (59%) have multiple impairments (Johnson-Kuhn, 1995).

According to the preliminary report Educational Outcomes for Colorado Students with Visual Disabilities, based on 98 randomly selected students with visual impairments (from those registered with the Colorado Instructional Materials Center as receiving vision or orientation and mobility services), 43 (43.9%) were identified with a primary disability of multiply handicapped (Ferrell & Suvak, 1993).

The PRISM Project: A National Longitudinal Study of Developmental Patterns of Children Who Are Visually Impaired, conducted by the University of Northern Colorado reported that at the end of the 5 year study, 59.9% of PRISM subjects (birth to five years) had been diagnosed with additional disabilities. Over one-third of the children with additional disabilities had conditions considered to be mild, while two-thirds were considered to be severe (Ferrell, Shaw, & Dietz, 1998).⁹

Low Birth Weight: U.S. Only

Blindness occurs mainly among children with birth weights below 1,000 grams (2 lbs 3 oz) at rates of 5 to 6% (Hack, Klein, & Taylor, 1995).

Cerebral palsy, hydrocephalus, microcephaly, blindness, deafness, and seizure disorders each occur at the following rates:

- 20% of infants with birth weight below 1,000 grams.
- 14 to 17% of infants with birth weight of 1,000 to 1,500 grams.
- 6 to 8% of infants with birth weight of 1,500 to 2,499 grams (Hack, et al., 1995).¹⁰

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Infant Registry

The following estimates are based on data collected for children from birth to 36 months of age, from the PRISM Project Registry of Early Childhood Visual Impairment Collaborative Group (PRISM Project Newsletter, 1996).¹¹ It should be noted that these figures include only those individuals registered with this project.

•The following presents the most frequently reported visual impairments among PRISM children (N = 165):

ROP	33 (20%)
Optic nerve hypoplasia	27 (16.4%)
Cortical visual impairment	22 (13.3%)
Albinism	14 (8.5%)
Coloboma	6 (3.6%)
Glaucoma	5 (3.0%)
Microphthalmos	5 (3.0%)
Aniridia	4 (2.4%)
Leber's Congenital Amaurosis	3 (1.8%)
Cataracts	3 (1.8%)
Anophthalmos	2 (1.2%)
Bilateral detached retina, glaucoma	2 (1.2%)
Cytomegalo virus (CMV)	2 (1.2%)
Septic optic hypoplasia	2 (1.2%)
Optic atrophy	2 (1.2%)
Others	33 (20%)

EDUCATION IN THE UNITED STATES

The Act to Promote the Education of the Blind

Reading Medium and Registration

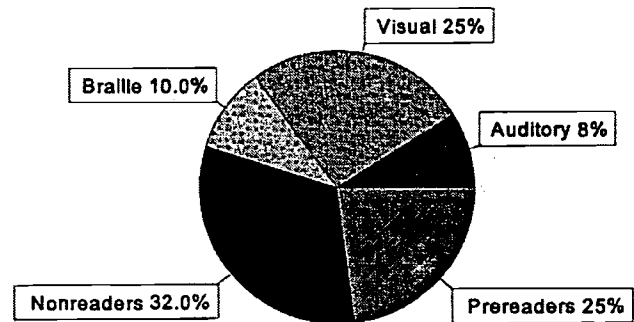
•The number of legally blind students registered with the American Printing House for the Blind under The Act to Promote the Education of the Blind for FY 1997 was 56,275 (American Printing House for the Blind, 1997).¹²

•Reading Medium

Of the 56,275 registered, students were classified as primary users of various reading media (American Printing House for the Blind, 1997) . Prereaders are students working on a readiness level or for whom the primary reading medium has not yet been determined. A nonreader is a student who does not fall into any of the named categories.

- Braille readers: 5,449 (10%)
- Visual readers: 14,341 (25%)
- Auditory readers: 4,228 (8%)
- Prereaders: 14,010 (25%)
- Nonreaders: 18,047 (32%)

Primary Reading Medium Used



Program Registration

Of this group of 56,275 registered, students were registered with the following programs (American Printing House for the Blind, 1997):

- State departments of education: 47,188 (84%)
- Residential schools for the blind: 4,588 (8%)
- Rehabilitation programs: 2,377 (4%)
- Programs for the multiply handicapped: 1,938 (4%)

Individuals with Disabilities Education Act (IDEA)

Students Receiving Vision Services Under IDEA Part B

According to the State Reported Data to the Office of Special Education and Rehabilitative Services, 24,877 students aged 6 to 21 received vision services during 1994 to 1995. This represents .5% of all students receiving services (U.S. Department of Education, 1996).¹³

Students Receiving Vision Services Under IDEA , Part H (0–2 years) in December 1993.

Of 165,053 infants and toddlers receiving services under IDEA, Part H, in December 1993, 6,201 Infants and toddlers received vision services (U.S. Department of Education, 1996).

Students with Visual Impairments (3–21 years) Receiving Services Under IDEA by Educational Environment, 1993–1994

The 24,877 students who receive vision services are served in the following educational environments (U.S. Department of Education, 1996).

- Regular classroom: 45.2%
- Resource room: 21.3%
- Separate class: 18.3%
- Separate school: 4.1%
- Residential facility: 10.6%
- Home-bound/hospital: .5%

Secondary School Completion Rates

In a study conducted by Wagner (1991), students aged 15 to 23 with visual impairments left secondary school during the 1985–86/1986–87 school years for the following reasons: 69.5% graduated; 15.2% dropped out; 13.7% aged out; 1.6% expelled.

Post-Secondary School Attendance and Success

According to a study and statistical profile compiled by Henderson (1995), attendance and success in post-secondary institutions in 1994 was as follows:

Attendance

- Freshmen with disabilities who reported being partially sighted or blind: 22% (28,402)
- Partially sighted or blind freshmen who reported attending four-year institutions: 69% (19,597)
- Partially sighted or blind freshmen who reported attending two-year schools: 26% (7,385)

Success in School: Comparison Within All Categories of Disabilities

According to Henderson (1995), students who were partially sighted or blind were more likely than other students with disabilities to have:

- Had an A average in high school: 33% vs. 20 %
- Tutored another student: 57% vs. 45%;
- Met or exceeded the requirements in English, math, foreign languages, and computer science: 82% vs. 75%
- Rated themselves above average or higher on measures of
 - academic ability: 62% vs. 44%
 - writing ability: 45% vs. 36%
 - ambition: 66% vs. 60%
 - intellectual self-confidence: 57% vs. 45%
 - emotional health: 49% vs. 43%

COSTS OF SPECIAL EDUCATION SERVICES

Exact current expenditures for special education services in the United States are unknown. One estimate is \$31.8 billion, or 12% of 1995–1996 expenditures for K–12 public education nationally.¹⁴

Average per- pupil expenditures for programs in visual impairment for 1985–1986 are: preschool - \$4,068; self-contained classroom - \$6,181; resource room - \$3,395 (Parrish & Chambers, 1996).¹⁵

(Data reported in Moore, M. T., Strang, E.W., Schwartz, M. et al. (1988). Patterns in special education service delivery and cost (U.S. Department of Education contract No. 300-84-0257). Washington, DC: Decision Resources Corporation.)

EMPLOYMENT OF YOUTHS WITH VISUAL IMPAIRMENTS

Results of the National Longitudinal Transition Study indicate that only 29% of the youths with visual impairments, between the ages of 16 and 21 years, were competitively employed 3 to 5 years following secondary school. This figure can be compared with 57% of youths with disabilities overall and 69% of youths in general who are employed (Blackorby & Wagner, 1996).¹⁶

NOTES

¹ National estimates of disability are closely linked to socioeconomic status and level of health care. In the United States, the child poverty rate is the highest among 18 industrialized countries (Children's Defense Fund, 1996). In 1994, 21.2% of children in the United States lived below the poverty line (Annie E. Casey Foundation, 1996). Furthermore, the percentage of children with private health insurance reached its lowest levels in the last 8 years (65.6%, or 46.3 million children) (U.S. General Accounting Office, 1996).

² Rates are based on the 1977 Health Interview Survey (HIS) for people under the age of 45. The rates are adjusted to help compensate for underreporting of severe visual impairment in the 1977 HIS.

³ Rates are based on Model Reporting Area (MRA) (U.S. Department of Health, Education and Welfare, 1973) statistics with a 100% augmentation based on a belief that the MRA statistics underestimate the prevalence rate of blindness by as much as 50%.

⁴ In developed and less developed countries, the available data underestimate the number of children and adults who are blind. In less developed countries, population-based surveys usually fail to take into account children who are in residential schools for the blind. In addition, certain blinding conditions are associated with high mortality rates. In developed countries, blindness registration data are often incomplete. In both situations, children with multiple handicaps are often not registered as visually impaired (World Health Organization, 1992).

⁵ When considering causes, it is important to remember that 79% of the world's population lives in developing nations. Ninety percent of blind children live in third world countries, where infections and poor nutrition, preventable causes of blindness, predominate. In developed countries, ROP and CVI, nonpreventable causes of blindness, predominate.

⁶ Worldwide, 350,000 new cases of xerophthalmia occur every year, with a 60% mortality rate one year after the onset of blindness (World Health Organization, 1992).

⁷ In the developed world, congenital cataract, when appropriately managed, is the only cause of visual defect to have recently shown a decrease in prevalence (Taylor, 1994).

⁸ In addition to retinal changes related to ROP, other ocular abnormalities are associated with ROP, typically in the threshold stage. These include myopia, astigmatism, anisometropia, and strabismus (Dobson & Quinn, 1996).

⁹ In order to avoid misinterpretations of the findings, oversimplification of the results, or unclear generalizations, the authors requested that conclusions from this report be presented with the caveats listed below.

Participants:

(a) All participants in this study were receiving services from early intervention and early childhood programs.

(b) None of the children in this study were without services, although the intensity, duration, and frequency of services differed across participants.

(c) Each of the infants in the study was being serviced by one of seven agencies specializing in serving children and adults with visual impairments. The services differed across sites and included center-based services, home-based services, a combination of the two, consulting services to generic and/or special education service providers, and testing/evaluation services only.

(d) The investigators hope to account for differences in individual cases as an ongoing part of the research, by exploring the effects of these service variables on outcomes rather than minimizing them or controlling for them.

Research Sites:

(e) Each of the seven sites included in this study specialized in serving individuals with visual impairments.

(f) Sites were selected to represent a cross section of geographic, cultural, ethnic, and socioeconomic factors.

(g) Both urban and rural services were represented.

(h) The relative failure of this study to attribute differences in development to degree of visual loss may have occurred because the services provided by the specialized agencies minimized the effects of visual disability.

(i) Sites differed in terms of public/private funding, resources available, licensing and certification requirements for teachers in each state, and age span served.

Diagnosis of Visual Disability:

(j) Each child in the study was initially deemed visually impaired and thus eligible for services by the host agency.

(k) The seven host agencies followed guidelines in their states for definitions of vision impairment, eligibility, and additional disability. These definitions varied somewhat across sites.

¹⁰ In 1993, nationally, 288,482 babies were born weighing less than 2,500 grams, making up 7.2% of all births, compared with only 6.8 % in 1985. This represents an increase of 6% over the 1985–1993 period (Annie E. Casey Foundation, 1996).

¹¹ The PRISM Project proposed to establish a model for a national registry of young children from birth to 36 months, by (1) working with public and private agencies in eight American states and one Canadian province to collect standardized epidemiological and demographic information on young children with visual impairments, and (2) developing a plan to implement the registry nationally in both the United States and Canada.

¹² American Printing House for the Blind is the official source of educational materials for legally blind students at less than college level in the United States (American Printing House for the Blind, 1997).

¹³ This figure significantly undercounts the actual incidence of visual impairment. For a discussion of child-counts under IDEA and their implications for the education of visually impaired students, see McMahon (1997).

¹⁴ This estimate is based on a projection of \$265 billion in current expenditures for K-12 public education for the 1995–96 school year. Twelve percent of \$265 billion is \$31.8 billion (Gerald & Hussar, 1995)

¹⁵ These figures represent the results of the last independent national special education cost study. The states were last required to report these amounts for the 1987–88 school year. According to Thomas Parrish, co-director of the National Center for Education Finance, two-thirds of the states do not know what they really spend on special education. The current estimate is that special education programs cost \$32 billion a year—a cost that is expected to rise—and that almost 40% of all new education dollars go to special education. Rising enrollment in special education is one of the major factors affecting special education costs (Council for Exceptional Children, 1997).

¹⁶ The prospect of employment improves slightly as these youths move into adulthood. According to Lighthouse International Statistics on Vision Impairment: A Resource Manual (1999), the unemployment rate for visually impaired adults 21 - 64 is 43.7%.

Appendix A

General Population Statistics

United States

1996 Estimates:

Total population: 265.2 million

Population under age 15: 58,344,000 (22%)

Birth rate: 3,978,000 (15 per 1000 population) (Population Reference Bureau, 1996)

World Population

Geographical Distribution

In 1994, world population was estimated to be around 5.6 billion. Only 1.2 billion people—or 21% of the world's population—live in regions classified as industrialized. The bulk of the world's population (79%) live in the developing regions. By far, the largest regions are China and southern Asia, each containing more than 1 billion people. Sub-Saharan Africa and Southeast Asia, the next largest regions, have more than half a billion inhabitants each. Asia alone contains about 60% of the total world population, followed by the Americas (North, South, and Central combined), with about 14%. Europe and Africa each hold between 12 and 13% of the world population (Lutz, 1994).

Birth Rates

Birth rates (births per 1,000 persons in the population) are by far the highest in sub-Saharan Africa (45 per 1,000 in 1994), followed at some distance by North Africa (33), western and Central Asia (33), and southern Asia (32). Among developing countries, only China, Hong Kong, and Taiwan have birth rates below 20, whereas all industrialized countries report birth rates well below 20 (Lutz, 1994).

Appendix B

Definitions

Incidence: Proportion of people who have visual impairments during a specific portion of time.

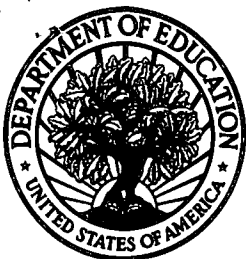
Population based prevalence: Proportion of people who become visually impaired during a specific portion of time.

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